

## **New Brunswick Lymescape Survey**

This survey is being conducted by the New Brunswick Lyme Disease Association Inc. – LymeNB and Mount Allison University.

Its purpose is to collect data on the experiences of people in New Brunswick whose lives have been influenced by Lyme disease in order to help determine the extent and impact of Lyme disease in New Brunswick. It is the intention to share the results at an upcoming MLA roundtable planned for the month of May of this year.

Please note that this survey is the first step of a broader Canadian Lymescape survey that is expected to be carried out in the not-too-distant future. The data collected in this first step will be merged with the data collected across Canada forming a pool of information that will serve to inform future research directions as well as public policy decisions.

If you have or have had Lyme disease or if you are a caregiver, or relative or friend of someone who has had or has Lyme disease, you are encouraged to add your voice to that of others by responding to this questionnaire. By submitting this survey, you will help us better understand the extent and impact of Lyme disease in New Brunswick.

**Please return your signed Consent Form (see next page)  
to this address: [Lymesurvey@mta.ca](mailto:Lymesurvey@mta.ca).**

**Or mail it to:**

**Lyme Survey, Attention: Vett Lloyd PhD, Professor, Department of Biology, Mount Allison University, 35B York St. Sackville, NB E4L 1G7**

## Consent form

### All survey information is confidential.

There is no obvious risk to you in completing the survey. **Your participation in this survey is completely voluntary – if you do not wish to participate, you need not submit the survey.**

Survey data will be stored securely for 5 years after the completion of this study, and then will be securely destroyed.

Survey results will be compiled and only presented anonymously; all results will be composite results and no names or personal identifiable information will be used. The anonymous survey data will be maintained in a databank but no personal identifiers will be associated with this databank.

**By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.**

Participant's signature \_\_\_\_\_

Date: \_\_\_\_\_

If you have any questions about this study, please contact Dr. Vett Lloyd, Dept. Biology, Mount Allison University ([vlloyd@mta.ca](mailto:vlloyd@mta.ca), 506.364.2509).

This research has been reviewed and approved by the Mount Allison University Research Ethics Board. If you have any concerns about this study, you may contact Dr. Lisa-Dawn Hamilton, Chair of the Mount Allison University Research Ethics Board, by phone (506-364-2618) or by e-mail at [reb@mta.ca](mailto:reb@mta.ca).

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Or mail it to: Lyme Survey, Attention: Vett Lloyd PhD, Professor, Department [ca](mailto:ca).  
of Biology, Mount Allison University, 35B York St., Sackville, NB E4L 1G7**

## Canadian Lymescape Survey

This survey is being conducted in collaboration with the New Brunswick Lyme Disease Association Inc. – LymeNB.

It has been designed to document the experiences of Canadians whose lives have been affected by Lyme disease. New Brunswick is the first province in which this survey will be running and we are asking your help in responding now so that the information gathered can be presented at a round table meeting of provincial MLAs scheduled in May 2019. The results will help us present the reality of people living with chronic Lyme disease and co-infections in New Brunswick

Your help is needed and time is limited to gather the amount of data necessary to have an impact. Please answer the questions **by March 31, 2019**. Feel free to share the survey with anyone living in New Brunswick or having spent time in our province who has been affected by Lyme disease and its co-infections. We would like to have as many responses as possible before the end of March.

As noted above, at some point in the not-too-distant future, this survey will be used throughout Canada. Your information will then be added to the responses from the rest of Canada.

Please note that all your data will be kept anonymous and used only in the aggregate.

Thank you in advance for your participation. Your input will help ensure that the voice of those affected by Lyme will be heard by our elected officials at the roundtable meeting in May.

Please return your completed questionnaire to this address: [Lymesurvey@mta.ca](mailto:Lymesurvey@mta.ca). Or mail to this address: Lyme Survey, Attention: Vett Lloyd, PhD, Department of biology, Mount Allison University, 35B York St., Sackville, NB E4L 1G7

### Section A General

1. I am a resident of
  - (province + county)\_\_\_\_\_
2. I have been diagnosed with Lyme disease by a healthcare provider.
  - Yes
  - No

3. I have been infected with Lyme disease since

- (year)\_\_\_\_\_
- Don't remember
- Don't know

4. I am filling this survey out for someone else.

- Yes (please indicate relationship)\_\_\_\_\_
- No

## **Section B**

### **Tick Bite**

5. I recall a tick bite prior to the onset of symptoms.

- Yes
- No

**If no, skip to question #16.**

6. The tick was attached for

- Less than 1 hour
- 6-12 hours
- 12-24 hours
- 24-48 hours
- Don't know

7. When the bite occurred, I was in

- (province or territory + county)\_\_\_\_\_
- Don't know

8. I had the tick tested

- Yes
- No
- Don't remember

**If no, or don't remember, skip to question # 13**

9. The tick was submitted for testing to which laboratory or place

- (please specify)\_\_\_\_\_

10. The species (kind) of the tick was identified.

- Yes. (Please specify)\_\_\_\_\_
- No
- Don't remember
- Unknown, did not receive the results

11. The tick was tested for Lyme disease or co-infections

- Yes
- No
- Don't remember
- Unknown, not given results
- Lab did not test

12. Please list test results, if known.

- \_\_\_\_\_

13. My healthcare provider treated me for Lyme disease based on a tick bite

- Yes
- No
- Don't remember

14. My treatment consisted of antibiotics

- Yes
- No
- Don't remember

15. My treatment was for

- 1 day/ A single dose of antibiotics
- Less than 14 days
- 14 – 21 days
- 28 - 42 days

### **Section C**

#### **Other Risk Factors**

16. Prior to being diagnosed with Lyme disease, I removed a tick from a pet

- Yes
- No
- Don't remember

**If you do not have any contact with pets, go to question # 21**

17. The tick was submitted for testing

- Yes
- No
- Don't remember

**If no or don't remember, skip to question # 21**

18. Please indicate where (to which laboratory or place) the tick was tested

- \_\_\_\_\_

19. The species (kind) of the tick was identified

- Yes (please specify)
- No
- Don't remember

20. The tick tested positive for *Borrelia burgdorferi*

- Yes
- No
- Don't remember
- Unknown, did not get results

21. I have family members who have been diagnosed with a tick-borne illness

- Yes. Please specify \_\_\_\_\_
- No
- Don't remember
- Unknown

22. I am aware of pets in my community who have been diagnosed with a tick-borne illness

- Yes. Please specify \_\_\_\_\_
- No
- Don't know

23. Prior to being diagnosed with Lyme disease, I worked in one or more of these occupations

- Construction
- Environmental assessment/conservation
- Farming and agriculture
- Logging
- Landscaping
- Land surveying
- Lifeguard at a beach
- Park/wildlife management
- Veterinary clinic
- Health care work with contact with bodily fluids (blood, urine or other)
- Other outdoor work involving exposure to bodily fluids \_\_\_\_\_

24. Prior to being diagnosed, I was involved in

- Camping
- Golfing
- Fishing
- Gardening
- Hiking
- Hunting
- Other outdoor activities or sports \_\_\_\_\_

#### **Section D**

#### **Rash (Erythema Migrans)**

25. I developed a rash (you can upload pictures if you wish)

- Yes
- No
- Don't remember

**If no or don't remember, go to question # 29**

26. Please describe the rash.

○ \_\_\_\_\_

27. My healthcare provider treated me for Lyme disease based on the presence of the rash

- Yes
- No
- Don't remember

28. My treatment consisted of antibiotics

- Yes
- No
- Don't remember

29. My treatment was for

- 1 day/A single dose of antibiotics
- Less than 14 days
- 14 – 21 days
- 28 - 42 days

## **Section E**

### **Onset of symptoms**

30. I developed Lyme disease symptoms after

- Being bitten by a tick
- Developing a rash
- Being diagnosed with cellulitis
- Having an immunosuppressive event/trauma
- Don't remember
- Don't know
- Other \_\_\_\_\_

31. Once infected, my symptoms occurred within

- 1-7 days
- 3-4 weeks
- 3-6 months
- 1-3 years
- Don't remember



- Don't know

32. My symptoms included:

- Fever
- Lingering and intermittent flu-like symptoms
- Recurring headaches
- Stiff neck
- Joint and muscle pain
- Fatigue
- Stomach/intestinal problems
- Facial drooping (Bell's Palsy)
- Numbness, tingling and burning sensations
- Sleep disturbances
- Chest pain with / or palpitations
- Psychiatric symptoms such as depression and anxiety
- Light and sound sensitivity
- Dizziness
- Dysfunction of brain including word retrieval and memory issues
- Lack of joint/muscles stability or function
- Other \_\_\_\_\_

33. My symptoms at the time of diagnosis were:

- Fever
- Lingering and intermittent flu-like symptoms
- Recurring headaches
- Stiff neck
- Joint and muscle pain
- Fatigue
- Stomach/intestinal problems
- Facial drooping (Bell's Palsy)
- Numbness, tingling and burning sensations
- Sleep disturbances
- Chest pain with / or palpitations
- Psychiatric symptoms such as depression and anxiety
- Light and sound sensitivity
- Dizziness
- Dysfunction of brain including word retrieval and memory issues
- Lack of joint/muscles stability or function
- Other \_\_\_\_\_

34. The period of time that went by between the onset of symptoms and an accurate diagnosis was

- Less than a week
- Less than a month
- Between 1 and 3 months
- More than 3 but less than 6 months
- More than 6 months
- More than a year
- More than five years
- More than 10 years
- More than 15 years
- Other \_\_\_\_\_

35. My three worst symptoms at the time of diagnosis were:

- 1- \_\_\_\_\_
- 2- \_\_\_\_\_
- 3- \_\_\_\_\_
- Other \_\_\_\_\_

36. My three worst symptoms now are:

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- Other \_\_\_\_\_

## **Section F**

### **Before Diagnosis**

37. Before being diagnosed with Lyme disease, I consulted or was referred to

- More than 3 doctors
- More than 5 doctors
- More than 10 doctors

38. I was referred to these specialists

- Cardiologist

- Dermatologist
- Infectious disease doctor
- Endocrinologist
- Gastroenterologist
- Hematologist
- Immunologist
- Internist
- Nephrologist
- Neurologist
- Ophthalmologist
- Psychiatrist
- Rheumatologist
- Urologist
- Radiologist
- Physical Therapist
- Chiropractor
- Naturopath
- Other \_\_\_\_\_

39. Before being diagnosed with Lyme disease, I was diagnosed with

- Rheumatoid arthritis
- Depression
- Anxiety
- Hormonal disorders
- Menopause
- Fibromyalgia
- Hyper or hypo tension
- Lupus
- Colitis
- Kidney disease
- Migraines
- Bell's palsy
- Parkinson's
- Thyroid problems
- Multiple sclerosis
- ALS (Amyotrophic Lateral Sclerosis)
- PTSD
- Irritable Bowel Syndrome (IBS)
- Cardiac conditions
- Chronic Fatigue syndrome

- Other \_\_\_\_\_

40. Before being diagnosed with Lyme disease, I underwent these tests:

- MRI
- Cat scan
- Colonoscopy
- Echography
- EKG
- EEG
- Bone Density
- Eye exams
- Neurological testing: EMG
- X-rays
- Lumbar punctures
- Cardiac testing
- Biopsies
- Other \_\_\_\_\_

## **Section G**

### **Diagnosis**

41. The stage of my illness when I was first diagnosed with Lyme disease is best described as

- Tick bite but no symptoms
- Rash (EM, classic bull's eye or irregular)
- Early or disseminated Lyme disease (flu-like, neurologic, cardiovascular, or musculoskeletal symptoms)
- Late stage UNTREATED Lyme disease (six months or more after onset of neurologic cardiovascular or musculoskeletal symptoms)
- Chronic Lyme disease (remained ill for at least 6 months after treatment with antibiotics for a maximum of 42 days)
- Don't know
- Other

42. I was diagnosed for tick-borne illness by:

- My family doctor or GP
- An internist
- An emergency physician
- An infectious disease specialist
- Another specialist (please specify) \_\_\_\_\_

- A physical therapist ( chiropractor, osteopath, physiotherapist)
- A naturopathic doctor
- A nurse practitioner
- Self-diagnosed
- Other\_\_\_\_\_

43. The diagnosis was based on

- Clinical symptoms and history of exposure
- Blood test
- Urine test
- Joint tap
- Cerebrospinal fluid
- Response to antibiotic therapy
- Other\_\_\_\_\_

44. My treating health practitioner(s) live (s)

- Less than 30 K from home
- Less than 100 K from home
- Less than 500 K from home
- Less than 1000 K from home
- More than 1000 K from home
- Other\_\_\_\_\_

45. I travel to appointments by

- Car
- Plane
- Train
- Bus

46. I travel to see my health practitioner

- Every 1-3 months
- Every 4-6 months
- Once a year.

## **Section H**

### **Testing for Lyme and co-infections and other tests since my diagnosis**

47. I underwent these tests for Lyme disease:

- Elispot
- Borrelia IgM/IgG ELISA
- Western blot
- Both ELISA and Western Blot (2 tiered testing)
- PCR-DNA
- Other \_\_\_\_\_
- Don't know
- Don't remember
- No testing has been performed

**If no testing or don't remember, skip to question # 53**

48. I had these results for the tests I undertook at these labs.

<b>TEST</b>	<b>APPROXIMATE DATE</b> ( each time a test was performed)	<b>WHERE PERFORMED</b> (eg. through Canadian Health Care system; through private labs; through research labs (university lab with no fee required); other (please specify)	<b>RESULT</b>

49. I was tested

- Less than 6 weeks after the first sign or symptom
- More than 6 weeks but less than 3 months after first sign or symptom
- More than 3 months after first sign or symptom
- More than 6 months after first sign or symptom
- More than 1 year after first sign or symptom
- More than 5 years after first sign or symptom

50. I was tested for co-infections

- Yes
- No
- Don't remember

51. I undertook these tests at these labs with these results.

INFECTION	TEST	APPROXIMATE DATE ( each time a test was performed)	WHERE PERFORMED (eg. through Canadian Health Care system; through private labs; through research labs (university lab with no fee required); other (please specify)	RESULT

52. I waited to receive the results of the testing

- Less than one week
- More than 1 week, but less than a month
- More than 1 month, but less than 6 months
- Greater than 6 months, but less than a year
- Greater than 1 year, but less than 5 years
- Greater than 5 years
- Never received the results

- Don't remember
- Other \_\_\_\_\_

53. Since being diagnosed with Lyme disease, I have undergone these other tests

- Brain/Head MRI
- SPECT scan
- CT scan
- Other \_\_\_\_\_

### Section I

#### Treatment *(type, duration and response)*

54. I began antibiotic therapy once I was diagnosed with Lyme disease

- Yes
- No

**If no, skip to question # 61**

55. I was prescribed these antibiotics

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_.

56. I was given antibiotics for

- 1 day/Single dose of antibiotics
- Less than 14 days
- 14-21 days
- 28 - 42 days
- More than 42 days (please specify)

57. I completed the full course of antibiotics.

- Yes
- No



- I stopped before the end
- Am still on antibiotics
- Don't remember

58. My response to antibiotic therapy has been:

- I had improvement in my symptoms (in less than one week)
- I had gradual improvement in my symptoms (1-4 weeks)
- I had improvement with long-term antibiotic use (more than 4 weeks)
- I had no improvement in my symptoms
- My symptoms got worse
- My symptoms got worse but improved over time
- Don't remember

59. I estimate the rate of improvement due to antibiotic therapy to be

- 0-20%
- 20-40%
- 40-60%
- 60-80%
- 80-95%
- 95-100%

60. I have been on an antibiotic treatment protocol for

- 1 month
- More than 3 months
- More than 6 months
- More than 1 year
- More than 3 years
- Other

61. My antibiotic treatment protocol has changed

- 1-3 times over the duration.
- More than 3 times
- More than 6 times
- Never

62. I use alternative treatments in the treatment of my Lyme disease.

- Yes
- No
- Not sure

63. I use these alternate treatments

- Acupuncture
- Chelation or detoxification treatments
- Colloidal Silver
- Electromagnetic energy therapy (eg. bioresonance therapy)
- Herbal protocols (eg. Cowden, Buhner, Bryon White, etc.)
- Herbal products (eg. Tinctures, Turmeric, Cat's Claw, etc.)
- Homeopathy
- Hyper-thermia or heat therapy
- Massage
- Medical marijuana
- Low Dose Naltrexone
- LDI
- Mental health counselling
- Nutraceuticals (eg Myers cocktails)
- Oxygen therapies
- Plasmapheresis transfusion therapy
- Probiotics (Theralac, VSL3, HMF Intensive, etc)
- Reiki
- Rife machine
- Stem cell therapies
- Lyme diet
- Other \_\_\_\_\_

64. My response to alternate treatment has been

- I had improvement in my symptoms ( in less than one week)
- I had gradual improvement in my symptoms ( 1-4 weeks)
- I had improvement with my symptoms (more than 4 weeks)
- I had no improvement in my symptoms
- My symptoms got worse
- My symptoms got worse but improved over time
- Don't remember

65. I estimate the rate of improvement due to alternate treatment therapy to be

- 0-20%
- 20-40%
- 40-60%
- 60-80%
- 80-95%
- 95-100%

66. I use the above-noted therapies

- In addition to my antibiotic therapy
- In lieu of any antibiotic therapy
- I use neither antibiotic nor alternate therapies.

**If you are using neither antibiotic nor alternate therapies, skip to question #69**

67. I estimate the rate of improvement due to the combination of antibiotic therapy and alternate therapy to be

- 0-20%
- 20-40%
- 40-60%
- 60-80%
- 80-95%
- 95-100%

68. The three most helpful therapies (including antibiotics) have been

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

69. I use other medications

- Antidepressants
- Anti-inflammatories
- Allergy medications
- Headache medication
- IVIG (Intravenous Immunoglobulins)
- Nerve-pain/anticonvulsant medications
- Over the counter pain relievers
- Prescription pain relievers
- Seizure medication
- Sleep medications

- Steroids
- Stomach medications
- Thyroid medications
- None of these
- Other \_\_\_\_\_

## **Section J**

### **Post Treatment**

70. I have completed my treatment.

- Yes
- No
- I had to stop

71. My symptoms

- Have never returned
- Returned as soon as I completed my treatment
- Returned within 6 months of completing treatment
- Returned more than 6 months later but less than a year
- Returned more than a year later
- Don't remember

72. Since completing my treatment,

- I am working or studying full-time and feel good
- I am working or studying full-time and I feel tired
- I am working or studying part-time and I feel I cannot do more
- I spend the majority of my time taking care of myself
- I cannot manage on my own.

## **Section K**

### **Retreatment (skip this section and go to section L if it does not apply)**

73. I stopped treatment

- 1 month ago
- 6 months ago
- 1 year ago

74. I stopped treatment

- On the advice of my treating healthcare professional
- Because I could no longer tolerate the treatment
- Because I could no longer afford the cost of treatment
- Because my symptoms had improved to an acceptable level
- Because I felt I was not improving
- Because my health had been virtually completely restored

75. My current symptoms are:

- Extremely severe; I am bedridden
- Severe; I cannot work nor have a normal social life
- Somewhat severe; I am limited in what I can do
- Acceptable; I can work and have a normal social life but sometimes I have symptoms
- Almost gone; my health is about 90-95% restored; I am no longer limited by my illness

76. I have resumed treatment

- Yes
- No

77. My current treatment protocol involves

- Taking prescription antibiotics exclusively
- Taking a combination of antibiotics and alternate treatments
- Using alternate treatment approaches exclusively
- Not pursuing alternative or antibiotic treatments

78. My symptoms

- Are improving
- Have not changed
- Have worsened
- Am not sure

## **Section L**

### **Overall Impact on my life**

79. I feel that my health

- Has been completely restored

- Has been almost completely restored; I function very well
- Is still improving
- Is at a standstill; I am neither better nor worse
- Is beginning to improve but has a long way to go before being restored
- Is poor and I cannot seem to get better
- Is hopeless; I will never be well again
- Other \_\_\_\_\_

80. I estimate that my health has improved by

- 0-20%
- 20-40%
- 40-60%
- 60-80%
- 80-95%
- 95-100%

81. I have been unable to work for

- 1 month
- 3 months
- 6 months
- 12 months
- 2-5 years
- 6 years or more
- I am still working

82. I have been on long-term disability for

- 6 months
- 1 year
- More than 1 year
- More than 5 years
- I am not on long-term disability

83. I have been unable to have an acceptable family and personal life for

- 1-3 months
- 4-6 months
- 6-12 months
- More than 1 year
- More than 5 years

- Other \_\_\_\_\_

84. I would characterize my mental outlook as

- Very good
- Good, but sometimes I suffer due to my illness
- Average, I have my good days and my bad days
- Poor, I find most days difficult to get through
- Terrible, every day is filled with anxiety, depressive thoughts and distress
- Unbearable, I have considered suicide or assisted suicide
- Other \_\_\_\_\_

85. I have the emotional support of my family and friends

- Completely
- Most of the time
- Yes and no
- Not really, I feel that I am alone, that they don't understand
- Not at all, I am on my own
- Other \_\_\_\_\_

86. Since being ill, I have lost

- My independence
- My job
- My interests and past-times
- My partner
- My children
- My family
- My savings
- My reputation
- My family doctor
- My social network
- My sense of self
- Other \_\_\_\_\_

87. I have considered taking my life

- A few times but I would never act on it
- Often but I would never act on it
- Sometimes
- Often
- I have made an attempt in the past

- I have tried several times to commit suicide
- Never
- Other \_\_\_\_\_

88. The three worst aspects of being sick are

- The pain
- The fatigue
- The medications
- The alternate treatments
- The lack of understanding
- The difficulties in trying to lead a normal life
- The lack of acknowledgement from the medical community
- The psychological effects
- The financial demands
- The lack of information
- The diet
- Other \_\_\_\_\_

89. Since being ill, I have gained

- A new appreciation for the ordinary things in life
- A new direction in my professional life
- A new direction in my personal life
- A closer relationship with family
- New friendships
- A greater self-awareness
- A deeper appreciation of my inner self
- A deeper connection with my spiritual self
- Other \_\_\_\_\_

90. In Canadian dollars, my out-of-pocket expenses for testing are

- Less than 500 CAD
- Less than 1,000 CAD
- Less than 2,500 CAD
- Less than 5,000 CAD

91. In Canadian dollars, my out-of-pocket expenses for visits to the doctor are

- Less than 1,000 CAD per year
- Less than 2,500 CAD per year



- Less than 5,000 CAD per year

92. In Canadian dollars, my out-of-pocket expenses for consultations with other health professionals are

- Less than 500 CAD per year
- Less than 1,000 CAD per year
- Less than 2,500 CAD per year
- Less than 5,000 CAD per year

93. In Canadian dollars, my out-of-pocket expenses for alternate treatments are

- Less than 1,000 CAD per year
- Less than 2,500 CAD per year
- Less than 5,000 CAD per year
- Less than 7,500 CAD per year
- Less than 10,000 CAD per year
- More than 10,000 CAD per year

94. In Canadian dollars, my out-of-pocket expenses for prescription drugs are

- Less than 1,000 CAD per year
- Less than 2,500 CAD per year
- Less than 5,000 CAD per year
- Less than 7,500 CAD per year
- Less than 10,000 CAD per year
- More than 10,000 CAD per year

95. I have health insurance over and above publicly funded health insurance to cover the cost of my treatment protocol

- Yes
- No
- Other \_\_\_\_\_

96. Since being ill, I have lost income in the order of

- Less than 5,000 CAD per year
- Less than 10,000 CAD per year
- Less than 25,000 CAD per year
- Less than 50,000 CAD per year
- Less than 100,000 CAD per year

97. Currently, my source of income is

- My full-time job
- My part-time job
- Unemployment insurance
- Social insurance
- Disability insurance
- My pension
- My long-term disability
- My partner
- Government programs (disabled persons, etc.)
- Other \_\_\_\_\_

98. I am able to cover the cost of my treatment

- Without any difficulty
- With some sacrifices
- More or less, but it is hard
- I have had to borrow money
- My family are helping me out
- I have done fund-raisers
- I have had to stop treatment
- I have not been able to afford any treatment

## Section M

### Overall assessment of your experience in Canadian Medical System

99. The doctors I have consulted about my symptoms have (please specify which doctor had which attitude if attitudes varied from one doctor to the next)

- Been open-minded \_\_\_\_\_
- Taken my symptoms seriously \_\_\_\_\_
- Been curious and wanting to learn more \_\_\_\_\_
- Have been ill at ease \_\_\_\_\_
- Have been confused \_\_\_\_\_
- Have laughed at me \_\_\_\_\_
- Have denied my symptoms \_\_\_\_\_
- Have been dismissive \_\_\_\_\_
- Have been exasperated and frustrated \_\_\_\_\_
- Other \_\_\_\_\_

(below is another way of handling this question)

Attitude	Dr. #1	Dr. #2	Dr. #3	Dr. #4	Dr. #5	Dr. #6
Been open-minded						
Taken my symptoms seriously						
Been curious and wanting to learn more						
Have been ill at ease						
Have been confused						
Have laughed at me						
Have denied my symptoms						
Have been dismissive						
Have been exasperated and frustrated						
Other						

100. My family doctor or GP

- Is knowledgeable about tick-borne illness
- Has some knowledge about tick-borne illness
- Knows little about tick-borne illness
- Denies the possibility of tick-borne illness
- Does not take my symptoms seriously
- Refuses to treat me

101. The specialists, including the ER doctors, I consulted were

Specialist (type	Knowledgeable	Somewhat knowledgeable	Receptive	Not knowledgeable	Diagnosed me	Referred me

e.g. orthopedist, internist ect...)	about tick borne illnesses	ble		ble	with something else	elsewhere

## Section N Demographics

102. I am

- Male
- Female
- Non-binary
- Prefer not to say

103. I was born in

- (year)
- Prefer not to say

104. The highest level of schooling I have completed is

- Some high school but did not complete
- High school diploma or equivalent (GED)
- Some college, but did not complete
- College diploma or certificate
- Some university but did not complete degree
- Bachelor's Degree
- Graduate Degree
- Prefer not to say

105. My current employment status is

- Employed full-time (more than 30 hours per week)
- Employed part-time (less than 30 hours per week)
- Full-time student
- Part-time student
- Homeschooled or taking on-line courses
- Not employed, looking for work
- Not employed, not looking for work
- Retired
- Disabled, not able to work (due to Lyme disease)
- Disabled, not able to work (for other reasons)
- Prefer not to say

106. In Canadian dollars, my current income is

- Less than 20,000 CAD
- Less than 35,000 CAD
- Less than 50,000 CAD
- Less than 75,000 CAD
- Less than 100,000 CAD
- More than 100,000 CAD
- Prefer not to say

107. I live with

- My partner or spouse
- My children
- My friend (s)
- Pets
- No one
- No pets
- Prefer not to say

108. I have

- No dependents
- 1-2 dependents
- 3-4 dependents
- More than 4 dependents
- Prefer not to say

109. My ethnic background is

- African

- Asian
- Caribbean
- European
- South Asian
- Central/South American
- First Nations
- Other \_\_\_\_\_
- Prefer not to say